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Regional Clinical Academic Palliative Care Forum: local research and practice coming together

Maja de Brito¹

Research Assistant, maja.furlan_de_brito@kcl.ac.uk

Bruno Fonseca²

Nurse, bruno.fonseca@ulsm.min-saude.pt

Barbara Gomes¹

Research Fellow, barbara.gomes@kcl.ac.uk

¹ King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, Bessemer Road, London SE5 9PJ, United Kingdom

² Matosinhos Local Health Unit, Palliative Care Team, Rua Dr. Eduardo Torres, 4464-513 Senhora da Hora, Portugal

Key points

- The establishment of a Clinical Academic Palliative Care Forum in the north of Portugal helped to disseminate and integrate the research that is conducted locally, by bringing together clinicians and researchers into the same room
- Through a program of meetings that are focused, with short presentations, interactive parts and time for networking, we have discovered breakthrough research 'at our doorstep' and identified research priorities, barriers and opportunities for collaborative research
- Direct outcomes of the Forum include a shared research strategy to guide future developments in the region, the creation of the *Ferraz Gonçalves Award* to promote the dissemination of exceptionally good research, and the replication of the initiative in other regions of Portugal
- Tips to those who wish to set up a similar initiative in their own region include: rotate meetings between sites, alternating clinical and academic; foster networking through interactive activities; and help research become more visible through incentives and training in dissemination

Introduction

A collaborative approach to research is essential for advancing the science in palliative care (PC). Clinicians have expert knowledge of what is happening day-to-day on the ground and access to patients, whilst researchers have the skills and time to design and conduct good quality studies. However, getting the two to work together has challenges, namely there are differences in agendas, perspectives and language, adding to the lack of allocated research time for clinicians.^{1,2} The Clinical Academic Palliative Care Forum is a regional initiative created by the DINAMO Project in the North of Portugal, with the aims of promoting exchange and facilitating collaboration between clinicians and researchers, and developing a shared vision for PC development locally. DINAMO is a five-year project aiming to enhance advanced training and research to optimise home palliative care in Portugal. This paper reports on the Forum's first year of activity and shares our experience, with a view to encourage and inform others who may wish to set up a similar initiative in their own region.

Setting the scene

It is only in the last two decades that PC has gained a notable push in Portugal resulting from the continued advocacy from PC professionals and several national directives and Laws already described in this journal.³ In 2012, a national PC network was established⁴, but still waits for regulation in order to be implemented. In 2014, the government set out a one-year time window for all hospitals and local health units to have a hospital PC support team.⁵

According to the Portuguese Palliative Care Association, there are currently 68 PC teams throughout the country, of which 31 are PC units with beds, 34 provide intra-hospital support and 22 provide home care;⁶ these figures result in one PC team per 160 000 inhabitants. However, Portugal has not yet reached a stage of development where PC is well integrated within the healthcare system, as recommended in the recent World Health Organization (WHO) PC resolution.⁷ Only 8.6% of countries worldwide have achieved advanced integration.⁸ There is a lack of recognition of PC needs by healthcare professionals, late referrals to PC, and most medical and nursing education has no basic PC training. The country is seeing increasing numbers of people dying in hospital.⁹

The research activity is also fairly recent. The first study we could find published internationally dated of 1995-98 (prospective audit of the last 48 hours of life of patients in a PC unit).¹⁰ There are now about 55 other studies indexed in Pubmed. The first Masters course in PC opened in Lisbon in 2002. Today there are seven accredited Masters degrees, three of which are based in the North (University of Porto, Portuguese Catholic University and Polytechnic Institute of Viana do Castelo).

The North region has been an important landmark in the Portuguese history of PC³; from its beginnings, as it housed one of the first PC services in the country (20 years ago at the Portuguese Institute of Oncology in Porto), to today's prominence as the region with the highest number of teams after Lisbon. With a population of about 3.7 million (35% of the national) and 32 000 deaths per year, the North is served by 21 PC teams (1 team per 217 000 inhabitants), of which 7 are PC units with beds, 13 provide intra-hospital support, and 9 provide home care⁶. The clinical teams meet four times a year since 2010 to discuss clinical issues and the coordination of care locally.

The Northern research activity is also fairly expressive within the country. By searching universities' repositories, library catalogues, abstract books, and PubMed we found 11 papers, more than 100 Masters dissertations and 40 conference presentations in the last two years.

How the idea of the Forum came about

The idea of a Regional Clinical Academic Forum was not new; it originally developed at the Cicely Saunders Institute to bring together clinicians and researchers working in South London (UK). After seeing the benefits achieved there, and realising that similar challenges to collaborative research were happening in the North of Portugal, we formed a coordinating team (a researcher and a clinician who had successfully worked together in a research study) and presented our intention to the coordinators of local clinical services and Masters courses who were generally very supportive. We obtained financial support from the Calouste Gulbenkian Foundation, and institutional support from the Regional Health Authority and the Portuguese Palliative Care Association. The terms of reference (available from the authors) were approved at the inaugural meeting in June 2014.

Organisational aspects

The Forum was designed to be accessible and practical. Currently with the total of 140 participants, we meet three times a year, rotating the meeting place to reach out to colleagues in different sites within the region, alternating clinical and academic hosts. The North covers 21 278 km², including urban and rural areas and making the journey for some as long as 350 km to attend the meetings.

The meetings are held in the morning, starting at 8.45am with breakfast and registration (1st networking point) and finishing around noon with one coffee break in between (2nd networking point) and lunch at the end (3rd networking point). We decided to do the meetings on Saturdays, recognising the difficulties clinicians face to take time off from their clinical work during weekdays. The provision of coffee break/lunch and a site tour is negotiated with the host organisation. This is particularly interesting when the host is clinical, as participants get to know the PC service/unit.

Discovering breakthrough research at our doorstep

The programs of the meetings are focused, with short presentations, interactive parts and time for networking. The opening and closing are times for health managers and policymakers, present upon invitation, to address the audience (e.g. Member of the Administration Board of the Regional Health Authority, Chief Executive of the Local Health Unit) and for broader topics of relevance to be discussed (e.g. national and international PC guidelines, presence of the North Region in national and international conferences). The program is then split into three parts: one focused on academic research, one focused on clinical research, and finally one group activity.

To identify studies to be presented at the meetings, we search university repositories, conference abstract books, and PubMed. We also consult with the Masters coordinators and use a snowball approach to identify studies conducted locally.

In the first meeting (June 2014) we focused on getting to know each other. The academic part was dedicated to the Masters coordinators, who presented a synopsis of the course, its history and current situation, 'opening the stage' for students who presented their Masters projects in the following two meetings (January and May 2015). The clinical part is usually focused on projects that are clinically orientated. At the last meeting of the first year of Forum's activity (May 2015), the 'clinical research' section was dedicated to multicentre studies, in response to an interest previously expressed by participants. Table 1 shows the topics presented.

During the meetings we have discovered there is valuable research being conducted 'at our doorstep'. An example of clinically relevant research with potentially international importance is the preparation of a saliva substitute and initial evaluation of its impact on quality of life of PC patients. Xerostomia or dry mouth is a problem frequently experienced by patients with advanced disease,

with physical, psychological and social implications.¹¹ The pharmacy of a local hospital developed an alternative that is easy to produce and much cheaper than the solutions available in the market. Their initial evaluation suggests improvements in comfort and quality of life for patients.¹²

Table 1. Research topics and speakers at the Forum meetings

<p>Academic</p> <ul style="list-style-type: none"> • Project DINAMO: Needs and optimisation of home PC (Dr Barbara Gomes, King's College London) • Family carers of patients in home PC (Maria João Cardoso Teixeira, University of Aveiro) • Psychological adjustment to cancer and self-efficacy in carers of PC cancer patients (Ana Maria Pereira, Portuguese Institute of Oncology in Porto) • Risk factors for prolonged grief in PC (Dr Diana Mota, Vila Nova de Gaia/Espinho Hospital Centre) • Healthcare professionals' perspectives on breaking bad news (Dr Maria Manuel Lopes, Matosinhos Local Health Unit) • Construction of "good death" in a residential home (Carla Manuela Dias Silva, Family Health Unit Prado) • Referral of AIDS patients to PC (Ana Daniela Paiva Guerra, São João Hospital Centre)
<p>Clinical</p> <ul style="list-style-type: none"> • Role of ketamine in non-controlled oncological pain (Dr Isabel Costa, Portuguese Institute of Oncology in Porto) • Impact of transfusion on symptom improvement in anaemic cancer patients (Dr Natália Loureiro, Tâmega and Sousa Hospital Centre) • Preparation of a saliva substitute and its impact on quality of life of PC patients (Alexandra Quintas, Porto Hospital Centre)
<p>Multicentre studies</p> <ul style="list-style-type: none"> • Symptom prevalence in PC patients (Dr Ferraz Gonçalves, Portuguese Institute of Oncology in Porto) • Validation of the Portuguese version of the Integrated Palliative care Outcome Scale (Barbara Antunes, University of Coimbra) • Attributes of home PC services preferred by patients and carers (Maja de Brito, King's College London)

The value of small group discussions and shared research priorities

Strategic analyses^{1,13} on the state of the science in PC indicate the urgency to improve quality and quantity of PC research and the need to have a clear steer. Aligned with these, we felt it was important to develop a shared research strategy to guide future developments in the region. We asked the participants what they thought would be important to research within the nine areas previously identified in a recent pan-European survey of research priorities in end-of-life care¹⁴: family and caregivers, non-cancer PC, home PC, PC in nursing homes, hospitals, symptoms, PC professionals, training and education programmes, and spirituality.

The diversity of participants' professional background and experiences also offered opportunity to jointly discuss topics like barriers in PC research in the region (e.g. lack of funding and clinical work overload) as well as opportunities that facilitate PC research (e.g. better dissemination of the existing activities and more training), as shown in Picture 1.

Picture 1. Forum participants discussing research priorities, barriers and opportunities



The participants identified a wide range of research and service-organisation priorities (Table 2). These range from exploring carers' needs to examining community and health system related issues.

Table 2. Research and service-organisation priorities shared by clinicians and researchers

Family and caregivers <ul style="list-style-type: none"> • Psychosocial profile of carers with their specific needs • Exploration of the concept of fear (from feelings of inadequacy to feeling overwhelmed) • Caring for carers: the role of healthcare professionals and volunteers • The carer and the social environment: attitudes/beliefs that inhibit the use of the resources available • Role of the informal network in carer support
Healthcare professionals, training and education programmes <ul style="list-style-type: none"> • Importance of a permanent integration of the physiotherapist in the PC team • Educational actions aimed at society in general (knowing one's rights when it comes to PC) • Educational actions aimed at healthcare professionals (stand-alone courses or PC disciplines instead of some hours of PC related topics within other subjects) • Update of a previous survey of PC teams' activity¹⁵ to know the current profile of professions and level of training in PC, identifying specific training needs
PC in the community <ul style="list-style-type: none"> • Coordination of care between the different levels of the health system • Access to drugs and technical equipment in community-based PC • Cost-effectiveness of home PC • What do patients and families value and feel as important in terms of home PC
PC in hospital and the control of symptoms <ul style="list-style-type: none"> • Nutrition and hydration: when the carers and/or healthcare professionals insist

<ul style="list-style-type: none"> • Role of physical and rehabilitation medicine in PC • Referring patients to PC: communication and organisational aspects • Clinical registers: problems arising from non-uniform registers between the services
PC in non-cancer conditions <ul style="list-style-type: none"> • Illness trajectories and referral criteria • Communication strategies for different illness trajectories • Evaluation/audit of screening tools to identify PC patients with non-cancer conditions: are we using the right tools? • Specific training for healthcare professionals on symptom control (e.g. renal and liver diseases) • Reorganisation of services to care for non-cancer patients
Spirituality <ul style="list-style-type: none"> • Exploration of healthcare professionals' opinions towards spiritual care • One-item assessment of spiritual support needs • Relationship between spirituality and symptom control • Concept and language of spiritual care as a training need for healthcare professionals • Reflexion groups on spirituality for healthcare professionals

Evaluating the Forum

We regularly evaluate the activity of the Forum by asking participants to fill in evaluation sheets at the end of the meetings. The feedback has been very positive with expectations met or exceeded. All participants so far agreed the objectives have been met and the contents have been useful and presented in a clear and understandable way (total of 86 evaluation sheets returned). Participants' feedback helped us improve some organisational aspects and decide topics for presentation. For example, following participants' suggestion, we have moved the meetings from working days to Saturdays, which resulted in better attendance and a more relaxed environment. Some flagged up that the scheduling and duration of meetings were a problem, because their workload rarely leaves them time for activities outside the clinical setting during working hours, and because meetings tended to last longer than planned. The schedule changed from weekdays to Saturday mornings as a consequence. The evaluation also confirmed that we should continue with the current three-part structure of the meeting (presentation of academically led research, clinically-driven research, and group activities).

Creating a Regional PC Research Award

The discovery of good quality and innovative research that we were not aware of made us think of ways to encourage not only the conduct of further good research but also better dissemination, to ensure the findings reach a wider audience. This led us to create a Regional PC Research Award, which was called the *Ferraz Gonçalves Award*. Named to honour the work of the founding director of the PC service at the Portuguese Institute of Oncology in Porto and the first president of the Portuguese Association of Palliative Care, the award distinguishes exceptionally good research conducted in the region in the last five years. The winner of the first edition of the award was Dr Helena Beça, a general practitioner (family doctor) who has recently completed a Masters in PC. She conducted a study which describes nearly all the deaths that occurred in an urban family health unit during a one-year period. Combining information from clinical records, interviews with general practitioners and bereaved relatives, Dr Beça found that the overwhelming majority died with

uncontrolled symptoms and no home care. None were asked where they would prefer to die; around two thirds died in hospital and one third at home.¹⁶ Unfortunately, this is the reality that clinicians in the North (but also in other regions of Portugal and of the world) encounter in their day-to-day clinical work, but up to now we had no evidence to show in Portugal. This study is an example we hope others follow in the future so we can change things and improve care locally and beyond.

Next steps

The success of the Forum led us to continue activity and replicate the initiative in other regions of Portugal. Linked through a common strategy and building on the Northern experience, three previous Masters students of the DINAMO Project are now creating Forums in their own regions (together with local clinical/academic colleagues): Dr Rita Canário in the Centre, Dr Ana Lacerda in Lisbon and Dr Vera Sarmento in the South (Alentejo and Algarve).

The focus of our work in the next year will shift from strategic discussions to acting upon the identified priorities and barriers by stimulating collaborations and making sure that funding and dissemination opportunities are not missed. Training sessions will be organised to improve the research skills of both clinicians and researchers (e.g. writing conference abstracts and papers).

Conclusion

For our region, the Clinical Academic Palliative Care Forum has proven to be an effective and timely way of disseminating and integrating information about the research that is conducted locally, by bringing together clinicians and researchers into the same room. The results from group discussions and the shared priorities identified are a starting point for action and a trigger for collaborative initiatives. We believe the initiative brings together research and practice in an innovative way that can help ensure our research translates into clinical practice and that our practice is evidence-based. Table 3 gives some tips to those who may wish to set up a similar initiative in their own region.

Table 3. How to create a Clinical Academic Palliative Care Forum in your region

<ul style="list-style-type: none"> • Scope interest and support in your region • Set up a coordination team of a researcher and a clinician with complementary skills • Write the Forum's terms of reference and agree with participants in the first meeting • Ask several clinicians and researchers what would be the most appropriate schedule and duration (have in mind that clinical responsibilities take priority) • Rotate meetings between sites to promote inclusion of the most isolated colleagues and alternate between clinical and academic hosts • Create a mailing list that disseminates meetings, local news and initiatives • Use a multi-channel approach to search for speakers like open access repositories, local library catalogues, local newspapers, lectures at PC related institutions. Talk to healthcare professionals and academics to ask if they know of any unpublished studies • Include small individually conducted research as it can provide valuable ideas if not results • Fosters networking and active participation by including interactive parts in the program • Prepare an evaluation sheet to monitor expectations and the value of the meetings for the participants. Provide space for comments on how to improve future meetings • Foster unpublished research to become more visible by creating incentives and support for submission of abstracts to conferences and papers to journals • Share your experience with others (e.g. presenting the activity of your Forum at the national PC congress in your country or in an international paper)
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Declaration of interest

The authors declare that there is no conflict of interest.

References

1. Sigurdardottira KR, Haugena DF, van der Rijtd CD, Sjøgrene P, Hardingf R, Higginson IJ, et al. on behalf of project PRISMA. Clinical priorities, barriers and solutions in end-of-life cancer care research across Europe. Report from a workshop. *Eur J Cancer* 2010; 46:1815-1822.
2. Hudson P, Streeta A, Grahama S, Aranda S, O'Connora M, Thomas K, et al. Establishment and preliminary outcomes of a palliative care research network. *Palliat Support Care*. June 19,2015 10.1017/S1478951515000723. [Epub ahead of print]
3. Capelas ML, Fernandes Coelho SP. European insight: Portugal is making great strides with the support of its national association. *Eur J Palliat Care*, 2014; 21:101-103.
4. Assembly of the Republic. [Law nr. 52/2012. Regulates the access to palliative care, defines the responsibility of the State regarding palliative care and establishes the National Palliative Care Network, subordinated to the Ministry of Health], September 5, 2012. [Governmental document in Portuguese]
5. Ministry of Health – Office of the Assistant Secretary of State of the Minister of Health. [Order nr. 10429/2014.] Determines that all hospital establishments and local health units of the National Health Service must ensure the existence of a hospital palliative care support team. August 12, 2014. [Governmental document in Portuguese]
6. Portuguese Association of Palliative care. *Palliative Care Services Directory 2015*. [updated 2015 Jul 23; cited 2015 Sept 17]. Available from: http://www.apcp.com.pt/uploads/diretorio_apcp_2015_07_23.pdf
7. World Health Association. *Palliative Care Fact sheet N°402 July 2015*. [cited 2015 Sept 15]. Available from: <http://www.who.int/mediacentre/factsheets/fs402/en/>
8. WHO and World Palliative Care Alliance. *Global atlas of palliative care at the end of life* [cited 2015 Sept 19]. Available from: <http://www.thewpca.org/resources/global-atlas-of-palliative-care/>
9. Sarmiento V, Higginson IJ, Ferreira PL, Gomes B. Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world. *Palliat Med* July 10, 2015.
10. Gonçalves JF, Alvarenga M, Silva A. The Last Forty-Eight Hours of Life in a Portuguese Palliative Care Unit: Does it Differ from Elsewhere? *J Palliat Med*. 2003; 6: 895-900.
11. Fusco F. Mouth care. In: Bruera E, Higginson I, von Gunten CF, Morita T (eds). *Textbook of Palliative medicine and supportive care*. Boca Raton: Taylor&Francis, 2015: 801-808.

12. Quintas A, Magalhães M, Rocha P. [Preparation of a saliva substitute: methodology and intervention of the pharmacist]. *Cuidados Paliativos* 2014;1: 77-78. [abstract in Portuguese]
13. Kaasa S, Radbruch L. Palliative care research – priorities and the way forward. *Eur J Cancer*. 2008; 44:1175–1179.
14. Sigurdardottir KR, Haugen DF, Bausewein C, Higginson I, Harding R, Rosland JH, Kaasa S, em nome do projeto PRISMA. A pan-European survey of research in end-of-life cancer care. *Support Care Cancer*. 2012 Jan; 20(1): 39–48.
15. Ferraz G, Almeida A, Antunes C, Cardoso A, Carvalho M, Claro M. et al. A Cross-Sectional Survey of the Activity of Palliative Care Teams in Portugal. *Am J Hosp Palliat Care*. 2013; 30(7): 648-651
16. Beça H. [Death in the Family Health Unit of Espinho in 2012]. Porto: Universidade Católica; 2015. [MSc dissertation in Portuguese]